



Advisory Committee on Disability Compensation

Camp Lejeune: Registry Question

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Camp Lejeune Background



- USMC training base in NC
- From the 1950s to 1980s, drinking water was contaminated with volatile organic compounds
 - Dry cleaning chemicals – perchloroethylene (PCE), trichloroethylene (TCE), vinyl chloride (a TCE degradation product)
 - Leaking underground storage tanks - benzene
- Over 1 million individuals potentially exposed



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Post Deployment Health Services Registries

- Agent Orange (AOR)
- Gulf War Registry (GWR)
- Ionizing Radiation Registry (IRR)
- Toxic Embedded Fragments (TEF)
- Depleted Uranium (DU)
- Airborne Hazards / Open Burn Pit (AHOBPR)



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Exposure Registries

- **Strengths**
 - Can be a tool for surveillance and epidemiology
 - Can be used for research, but must recognize the limitations
 - Can use to build cohorts
 - May collect limited information on occupational exposure and disease in large populations
 - May provide an overview of some disease trends
 - A registry exam is not a compensation exam.
- **Weaknesses**
 - Significant inherent limitations in the use of registries to draw inferences regarding the presence or strength of an association between an exposure and a health outcome* (Critical research issue)
 - Issues include:
 - Self-reporting of an effect
 - Misclassification
 - Recall Bias
 - Self-selection
 - Missing data
 - Large populations: Studies may lead to statistically significant but not clinically significant results
 - Cost, maintenance of data and security issues.

*National Academies Press: Assessment of the Department of Veterans Affairs Airborne Hazards and Open Burn Pit Registry. 2017



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Camp Lejeune Registries

1) CLHDW Notification Database (target 1953-1987) - Started in 2007. It is a mailing list (with emails, addresses, phone #) for dissemination of information. It does not require proof of residence to join. Most information was provided online or via the call center. Initially, the USMC manually added ~49K names/addresses. For ~150K names/addresses the USMC requested the IRS contact them on the USMC's behalf via letter to encourage the Veteran to call or come to the website to register. This database currently has >263K unique contacts.

2) Camp Lejeune Family Housing Records (1941-1987) - Camp Lejeune has a record of family housing unit occupants. The index cards are in a searchable database.

3) Marine Corps Unit Diary Database (MUDD) (1940-2005) - From 2014 to 2015, the Marine Corps scanned ~69 million images of historic Muster Rolls (microfilm and microfiche) that were located at MCB Quantico and the National Archives. The images are in a searchable database by year, description, RUC or SSN, organizational unit, location, MMSB reel number (if applicable); and/or through a Full Text search. A search tool was developed for 1950-1990 to facilitate queries.

4) Defense Manpower Data Center (DMDC) (Service Members and civilian workers): has electronic data for Marines back to 1975 (12 years of the 35-year period covered by the health care law) and data for civilian workers to 1973. USMC and ATSDR query the data using Reporting Unit Codes (RUC) for units based out of Camp Lejeune. Using this data shows ~200K Marines at Camp Lejeune.



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Camp Lejeune Registries



http://www.marines.mil/clwater/

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Join the Notification Database Today

The Marine Corps encourages all those who lived or worked at Camp Lejeune in 1987 or before to register to receive notifications regarding Camp Lejeune Historic Drinking Water.

REGISTER HERE

Or [Update Information](#)

Camp Lejeune Historic Drinking Water

In the 1980s, some of Camp Lejeune's drinking water wells were found to be affected by unregulated industrial chemicals. We do not know if past exposure to these chemicals in Camp Lejeune's drinking water caused adverse health effects in specific individuals. Our goal is to use the best available science in an effort to provide our Marine Corps family members the answers they deserve and keep them updated as information becomes available. Since 1991 we have supported scientific and public health organizations that are studying these issues. We continue to work diligently to identify and notify individuals who, in the past, may have been exposed to the chemicals in drinking water.

Registration Summary

See the number of people registered in your state.

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Activities

- DoD: Created a self-reported registry:
 - To notify Veterans of possible exposure
- Agency for Toxic Substance Disease Registry (ATSDR):
 - ATSDR did NOT create a Camp Lejeune registry
 - Conducting a series of DoD funded epidemiology studies
 - Created CL study cohorts, based on the lists; includes CL military, CL civilians, Camp Pendleton military and CP civilians. CP military and civilians are comparison groups used in ATSDR epidemiologic and mortality studies.
 - Led Community Assistance Panels from 2005-present
- VA has negotiated with ATSDR to take over the CL Cohort (at the completion of the cancer outcome study currently underway) for long-term morbidity and mortality analyses.
- Well-designed epidemiologic studies offer the best scientific approach and the most cost-efficient means of assessing health outcomes in the CL population.
 - This is the approach used by ATSDR.



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Exposure registries are not like “disease registries”.

- Establishment of a registry would have marginal benefit to Veterans and Family Members.
 - Legislation would be required to mandate and fund the CLR.
- An advantage of a registry is the ability to contact members when there is new information.
 - The USMC already maintains and regularly uses an extensive registry database of names and addresses for this purpose.
- There are significant and inherent limitations in the use of registries to draw inferences regarding an association between an exposure and a health outcome.
 - Exposure registries are not like “disease registries”.
 - Recall bias, self-reporting bias and self-selection bias all severely hinder the use of self-reported registry data in research.
 - Cost and maintenance



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Bottom Line:

- A Registry would do little to answer the questions of Camp Lejeune Veterans and Family Members. It would use resources that could be better used for following this cohort for health issues and studies of other health consequences.
- VA has already negotiated with ATSDR to take over the CL Cohort (at completion of the current cancer outcome study) for long-term morbidity and mortality analyses.
- Well-designed epidemiologic studies offer the best scientific approach to assess CL health outcomes.
 - This is the approach used by ATSDR.

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